The Brain-Damaged Infant  
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The issue of life expectancy is perhaps no more controversial within any disability group than it is in the instance of the brain-damaged infant. This controversy has developed in part as a result of a number of physicians being willing to arbitrarily establish an estimated life expectancy based on their experience over the course of their practice, without regard to any reliable statistical analysis and without taking into consideration the confounding variables that can so significantly influence issues of life expectancy (e.g., institutionalized versus home-based care).

The controversy has been exacerbated by the release of the study in 1982 entitled "Life Tables for Institutionalized Mentally Retarded" (Eyman, et al). The willingness to broadly extrapolate the conclusions of this article to populations of individuals who are not part of the normative study has set a significant and, quite frankly, dangerous precedent.

The basic conclusions reached by the study are valid, and both the original 1982 study and the follow-up study published in 1990 represent some excellent epidemiological and life table research. The concern expressed here is not so much with the research methodology as with the tendency of individuals to apply the conclusions broadly on an unrestricted basis.

It is critical that the rehabilitation professional and physicians relying on such studies understand the methodology employed, the normative population and the limitations of the research, so that intelligent decisions can be made when extrapolating these conclusions to life expectancy in a given patient.

A variety of critical factors that influence issues of life expectancy in the brain-injured infant should be assessed in the rehabilitation evaluation and considered in the development of life care planning recommendations. The following represent some of the more critical factors:

1. The degree of responsiveness to external stimuli: The extent to which the brain-damaged infant interacts with the environment and particularly with family and caregivers within that environment can be an important factor. Certainly this tends to reflect the degree of cognitive versus motor deficits that may be influencing the infant's development. The child who is more cognitively alert, recognizes family from strangers and is more responsive in interacting with and bonding to family and caregivers tends to thrive within the environment much more effectively than more significantly impaired children.

2. Growth factors in relation to chronological age: The child who fails to meet growth expectations in his or her developmental milestones may demonstrate a failure to thrive that can directly affect life expectancy. This is not a conclusion that can be reached easily for younger infants, but as the child progresses beyond the age of two, such assessments are more easily made.
3. Tube feeding: The child who is unable to take food by mouth; has poor sucking, chewing and swallowing capacity; and requires tube feeding is also going to see a negative impact on life expectancy. Care requirements increase, as does the need for medical support, and this places the child at higher risk for complicating factors.

4. Immobility: The child who remains non-ambulatory, with little voluntary purposeful movement of the extremities (spastic quadriplegia), and who fails to reach motoric developmental milestones is at much greater risk for complications such as contracture deformities, renal difficulties, skin care complications, bone demineralization, restricted growth and related orthopedic complications. All these represent a potential negative influence on life expectancy.

5. Seizure disorders: The existence of a seizure disorder (e.g., significant breakthrough seizures) that cannot be brought under control with medication also places the child at higher risk for a reduced life expectancy. Depending upon the severity of the seizure disorder, this can also influence a failure to thrive.

6. Associated complications: Additional factors that may influence life expectancy are the existence of cardiac problems, upper respiratory and pulmonary distress, and complications associated with aspiration. Each of these problems will increase the likelihood of hospitalization and more intensive medical follow-up, and may also require higher levels of follow-up nursing services. Each can be a significant threat to life expectancy if not managed properly as well.

A portion of the rehabilitation professional's role in life care planning is to properly manage the disability and the problems associated with these complicating factors. This must be considered in any assessment of life expectancy, because of the influence of appropriate preventive programs and responses to complications that influence life expectancy and that were not considered as confounding variables in the individual research projects that were used to establish life expectancy tables. The following examples are set up as complements to the previous list of six factors negatively influencing life expectancy:

1. Utilizing educational and behavioral support programs: Programs such as this can significantly influence the child's responsiveness to external stimuli and make a difference, even in the instance of children with a very low capacity for stimulus response. Such programs are designed to work with children at whatever level of function they can demonstrate and can be important not only in helping to stimulate development and then maintain levels achieved, but also in provision of family support and maintenance of the family support unit.
2. Appropriate medical care and support staff involvement: When growth is a
concern and there is a question of whether the infant is beginning to demonstrate failure to thrive, intervention strategies must include appropriate levels of support care and integration of therapy programs in the daily routine. This helps maintain the highest possible level of muscle tone, nutrition and cognitive development and can positively influence a child's potential to thrive.

3. Feeding support: The child who is tube fed needs assistance at two levels. The first is appropriate levels of nursing services (typically an LPN), with proper monitoring and care of the tube, proper nutrition and careful monitoring of the child. The second level is application of weaning techniques to remove the child from tube feeding overtime. This may involve working on sucking, chewing and swallowing behavior, initially with the occupational therapist and subsequently with the speech and language therapist when appropriate.

4. Integration of physical, occupational and speech therapy programs within the structured daily routine: We can all understand the importance of physical therapy, occupational therapy, and speech and language programs for these children and particularly those with immobility. Beyond these direct therapeutic inputs, it is important to also understand that the information provided by these therapists to the family and support staff must be integrated into the daily routine, so that an appropriate level of ongoing therapeutic intervention is maintained.

Postural changes to break up congestion and promote drainage can be one positive side effect. Other benefits include the reduction of contracture deformities and the lessening of the potential for renal complications. Speech and language should be considered even when the development of verbal communications is not possible and we are restricted to working on nonverbal communication skills.

5. Seizure care and support: The most effective approach in the life care plan when working with seizures is an appropriate level of nursing support supervision coupled with medical care and follow-up and routine blood level checks to maintain a therapeutic level of seizure medication in the bloodstream. All other appropriate medical recommendations must also be integrated into the life care plan.

6. Associated complications dictating concomitant levels of medical and nursing support: Issues such as upper respiratory and pulmonary distress and aspiration can be particularly responsive to appropriate levels of nursing care with preventive programs built into the daily routine.

It is easier to deal with these problems preventively than to be responsive in treatment, and this should always be the basic philosophy of the life care plan. Certainly direct medical input into recommended support modalities must be obtained, as it relates to other complications (e.g., cardiac problems).
7. In addition to the direct responses to the problems that may influence life expectancy, it is important for the life care planner and case manager to also recognize that indirect benefits are obtained through a range of other services (e.g., educational support, social interaction). The stimulation obtained by changing environments and interacting with other children can provide important additions to quality of life while also stimulating the child to reach the highest level of cognitive, social, behavioral and motoric development.

Two publications are of particular importance, at least in terms of the frequency with which they are used by defense attorneys and insurance carriers when trying to develop a legitimate understanding of reduced life expectancy in the brain-injured infant. These publications will be discussed first, followed by a bibliography.

The discussion of these articles is not designed to criticize the research methodology, statistical analysis techniques or even the basic conclusions reached. The concerns expressed deal with the utilization of these studies and their misapplication to normative populations not actually participating in the research. The first of these was a monograph by Eyman, et al. (1987) entitled, "Life Expectancy and Mental Retardation."

The study reviews literature and in its initial pages draws some important conclusions regarding that literature. The authors found that overall mortality has declined over the previous decades, but pulmonary disease still continued to be the number one cause of death, accounting for as much as 50 percent of all deaths prior to that time. This points to particular concerns with the more profoundly retarded, who are immobile and demonstrate significant feeding difficulties, with the potential for aspiration.

Suggestions for improving survival included the use of smaller and more specialized placement facilities, intensive monitoring, specialized nursing care, restrictions on the admission or transfer of children less than five years of age to larger facilities and limits on the number of admissions or transfers to the same facility over a comparatively short time. Despite the recognition that improvements such as these could have a positive impact on life expectancy, the study reached conclusions that, when applied generally to all mentally retarded, ignored all these recommendations and the differences resulting from level of retardation, level of mobility, level of feeding capability, age differences and environmental differences.

The population studied in this monograph consisted of all admissions to the Pacific State Hospital from 1927 until the end of 1974, with follow-up on these patients until December 31, 1976. Although the population was split into two groups-those admitted between May 1927 and December 1959 and those admitted between January 1960 and December 1974-there is still significant concern over whether the data collected on patients going back to 1927 represent a reasonable base for conclusions to be drawn regarding infants in the
1990s.
Ten-year-survival rates by age and IQ were provided, which helped break down some of the information, but no distinction could be drawn between patients in a state institutional setting and those in home-based or small-facility settings. It is also important to recognize that by using a ten-year-survival rate, one is splitting the population between those who survive ten or more years and those who fail to. This raises the issue of the self-fulfilling prophecy. If an assumption is made regarding a significantly shortened life expectancy, and appropriate medical, nursing and other support systems are funded only until that age and then withdrawn, the result will be an artificial shortening of life expectancy as a result of a self-fulfilling prophecy.

The study does recognize that the longer the infant lives, the more likely it is that he or she will attain an older age. This is important in recognizing that survival of the critical first year post-birth can in and of itself make a significant difference in long-term survivability.

The contention that survival rates in such institutional settings (particularly when data are drawn from as early as 1927) can be appropriately applied to community-based children is of significant concern, particularly when earlier in the same study the statement was made that previous research found overall mortality of retarded residents higher in institutions than in community settings. That fact is apparently ignored when the authors suggest that it is appropriate to draw direct comparisons.

Another important statement within the study reveals that "historically most studies on the mortality of the mentally retarded people have been restricted to institutional populations." It is extremely important to recognize the difference in these populations and also to recognize the differences related to level of medical and health related support care services.

In a follow-up article by Eyman, et al. (1990), the earlier life table studies were updated for the mentally retarded. This study attempted to more carefully delineate the mentally retarded population by separating them into groups based on specific levels of functioning. Tube feeding, immobility and seizure disorder were considered. Borderline and educable mentally retarded individuals without associated complicating conditions were found to have near-normal life expectancies.

I believe this study helps to significantly reduce the problems associated with the earlier life table monograph. Concern is still expressed regarding a failure to differentiate between levels of available medical and support care, but the most important concern is the direct application of these statistics without the intervening variable of a medical and rehabilitation evaluation. Such statistics are important to consider as one part of the data base upon which a final conclusion can be drawn in life expectancy.

To use them independently without such evaluations seems arbitrary and runs a high risk of the concerns previously expressed regarding the self-fulfilling
prophecy. I do not believe that it can be considered acceptable for basic data in each of these areas to simply be given to an individual, who then goes to the life tables established in these studies and assigns a life expectancy, with no further input from treating physicians, rehabilitation professionals or case managers.

In the end it is preferable that a treating physician and/or an independent medical examiner who has actively evaluated the child and not just the records be involved in assessing life expectancy issues.

Some of the popular literature that gives us brief insights into that population would be particularly interesting to individuals involved in such assessments. A good example is the New York Times article (Lewin, 1990) that discusses the growing crisis in the United States resulting from the aging severely mentally retarded population who are beginning to outlive their families. The article pointed out the critical concern of limited availability of governmental resources to deal with this population. At the same time, the Orlando Sentinel (November 1, 1990) reported on the extensive waiting list that exists in the state of Florida for individuals in this population who are seeking services through government resources. Similar information can be obtained in other states, including Pennsylvania, where an estimated 7,000 individuals who were found to be multi-handicapped and mentally retarded are currently on waiting lists for services through group homes, intermediate care facilities for the mentally retarded and related institutional settings.

The readings presented in the following bibliography include general informational articles on issues related to cerebral palsy and mental retardation, which, although not specifically establishing life tables, do discuss issues that are relevant to treating complications that can influence life expectancy. Additional articles are provided that discuss life expectancy issues and should be considered carefully when extrapolating conclusions, particularly if the studies were based in settings outside the United States.

**Cerebral Palsy**


Koffman M.: Proximal Femoral Resection or Total Hip Replacement in Severely


*Mental Retardation*


Works Cited:


